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ABSTRACT

The handbook focuses on ways in which local Association for Retarded Citizens (ARC) groups can meet the needs of young parents with retarded children. The importance of recruiting young parents is stressed, and perceptions of these parents toward the ARC are considered. Local ARC units are advised about ways to find young parents in the community, including using brochures with which parents can check their child's development, offering to provide inservice training on mental retardation to professionals in the community, and setting up a speakers' bureau. Programmatic thrusts, such as the "pilot parent" effort (which trains experienced parents of children with handicaps to work with parents of newly diagnosed children), educational advocacy, respite care, and recreational programs. Additional services developed by ARCs include toy lending libraries, adaptive equipment exchanges, and parent libraries. (CL)

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TO OUR FUTURE . . . AND THEIRS

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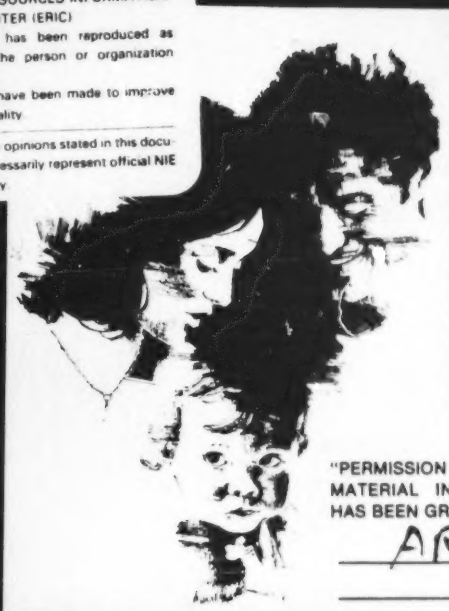

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A Handbook on Involving Young Parents in the ARC

Association for Retarded Citizens

EC180553

To our future . . . and theirs

A Handbook On Involving Young Parents In The ARC

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Dear ARC Leader:

As I travel around the country speaking to ARC units, I have become alarmed because I am not seeing the 'younger set' of parents that I feel are needed in the ARC family. Not only does the ARC need young parents, but young parents need the ARC.

I remember, as I look back, how important this organization was to us as a family and why we got involved. The ARC was the only group then in existence that addressed the needs we had when our daughter, Kris, was young. We needed the interaction with other parents, and most of all we needed someone to help us get services for Kris.

Although that was sometime ago, things have not really changed that much. Some needs may be different, but the ARC is still the only organization that is totally concerned with the rights and needs of persons with mental retardation and their families.

Parents' emotional needs, I am sure, are no different than ours were. I want them to experience the same closeness and responsiveness from the ARC we experienced. Even today when I am angry about an issue, I use my ARC as a resource and for problem solving. That means that as a parent I have to participate to make things happen; but it's nice to know that an organization of this size has far more clout than I alone can have. There is strength in numbers.

The ARC must reach young parents. We must seek them out, listen to their concerns and involve them in meaningful ways that will meet their needs. We need them, but we must make them feel welcome and needed. Please encourage young parents to join us in our fight for the rights of persons with mental retardation.

Dee Everitt

Dee Everitt, President
Association for Retarded Citizens - 1983 - 1985

'This woman called from the ARC and asked how I was doing. I didn't want to talk to her. She kept calling and eventually broke through to me. They were not willing to give up on me; I will always remember that. I will **always** *remember that.'*

Suzanne Denson
ARC Clear Creek, Texas

'Phillip was 10 months old and I had searched everywhere for help. My sister called the ARC, and I remember well the day; for as a result of her call, another parent called me. I had given up and was considering suicide as a way out when she called. That listening parent from the ARC is why I'm here today helping other parents.'

Phyllis Wilcox
ARC Northern Virginia

'We found out about the ARC shortly after Stacey was born with Down syndrome. One of the infant care nurses at the hospital happened to be the mother of a Down syndrome son, and she put us in touch with the ARC. They alleviated our fears, — fears of the unknown.'

Sidney and Shirley Seruntine
Metairie, Louisiana

These stories and many more like them reflect what happens when young parents discover the ARC. Yet in many cases that discovery process may take years if it happens at all.

This membership handbook focuses on parents of young children with mental retardation, their needs and how the ARC can reach out to them. We'll share with you services the ARC has developed to meet the needs of young parents and in doing so, involved them in the ARC. We'll also look at some old ideas that still work -- if we use them.

The involvement of young parents is our greatest membership challenge. We need their ideas, their support, their enthusiasm and their future leadership. We feel this handbook offers you a great start in answering that challenge.

Looking at Ourselves

People join organizations at first because of what the organization can do for them directly and personally. If our efforts to involve more parents of young children are successful, it will be because we offer programs and services which are relevant and meaningful to them and their children.

Before attempting to recruit and involve younger members, ARC leaders need to ask:

- *Are we knowledgeable about and actively involved in issues of concern to young parents?*
- *Do we have services and programs specifically geared to young children and/or their parents?*
- *Are we familiar with all resources for young children with mental retardation in our community?*
- *Can young parents get needed information and assistance through the ARC?*
- *Are we interested in involving young parents to meet* **our** *needs (for future leadership) or theirs?*

Young parent involvement in the ARC movement will ultimately depend on how well the Association responds to their needs. Although, over the years the Association has been the single most important force in improving conditions for children and adults with mental retardation and their families, we cannot expect people to join because of what we've done for them in the past. If we do a good job in meeting their needs, more young parents **will** join the ARC.

Needs of Young Parents

The Association was founded in 1950 by a group of parents because their children who were mentally retarded simply had no access to educational services. If the need for services brought these parents together, what kept them together was the support system they found within the ARC. They found other parents with the same problems and needs as their own, and have remained with the ARC over the years because we have continued to be responsive.

Although the services the ARC has worked for have changed over the years, the basic needs of young parents have not. They still need the emotional support and practical information other parents can give.

Yet as we consider these needs, we must also realize times have changed dramatically. What motivated a parent to join the ARC five or even 10 years ago may not have meaning for a parent today.

Some of the factors affecting young parent involvement are:

- *more single parent families -- over one-fifth of all children live with one parent.*
- *more households where both parents work outside the home.*
- *more volunteers nationally, and*
- *more meaningful volunteer experiences being sought -- a trend for volunteers to be more particular about what they give their time to.*

What does all this mean? It means we must carefully consider the needs of young parents, and the pressures they face in order to effectively respond to them.

Perceptions: How Young Parents View The ARC

No matter how well we respond to their needs, some young parents will still be reluctant to get involved in the ARC.

There are a number of reasons parents may not come to the ARC in the early years of their child's life. Some have difficulty accepting their child's handicapping condition. Others are not ready for involvement until later in their child's life.

But many times parents do not join because they are either uninformed or misinformed about the ARC. Let's look at some of the reasons why:

Because their child is now receiving adequate services, parents believe those services will continue to be available throughout their child's life.

It is often a shock to parents when, as their child grows older, they find that services are inadequate, or even nonexistent. But we are far from having all the services needed and young parents should be aware of that fact.

Some parents believe that the battle for services is over — that what's available now for their children will always exist.

As past experience demonstrates, we cannot afford to be complacent about the progress we have made in obtaining services for people who are mentally retarded, or we risk losing those services.

Parents perceive the ARC as an organization primarily concerned with the needs of adults with mental retardation and their families. They don't feel the Association is interested in the needs of their young children.

In recent years it was necessary for the ARC to put a great deal of energy into seeing that appropriate vocational and residential services were available to adults with mental retardation. The ARC must continue to work for services for adults but we cannot neglect the needs of young children or their parents.

Professionals don't use the term mental retardation in the child's early years so parents don't look to the ARC to meet their needs.

Professionals are sometimes hesitant to use the term mental retardation. In some cases, it is not in the best interests of the child to use a label that can be, unfortunately, a stigma. At other times, professionals may simply be uncomfortable in discussing an issue as emotionally charged as mental retardation. The ARC should be very sensitive to the use and misuse of labels.

Parents belong to other organizations which they feel address their needs more directly than the ARC.

It is essential that young parents be made aware of our successful track record in securing rights and services for people with mental retardation and our continuous efforts on their behalf on the local, state and national levels. While it is only natural that they belong to other organizations, young parents should be ARC members as well. Without their support we cannot continue to be as effective.

Finding Them

After your ARC unit decides what it can offer to young parents (based on an understanding of their needs and perceptions), your next task will be to find them.

In trying to identify young parents, your ARC unit will be working closely with professionals. You may be frustrated by their lack of awareness of the ARC movement, but your efforts to involve young parents should have the added benefit of increasing professional awareness.

Another source of frustration in working with professionals will be the issue of confidentiality. Professionals have an ethical and legal obligation to protect the privacy of their clients. Although it may sometimes seem that your efforts to provide services are hampered by the strict rules regarding confidentiality, it is in our best interests to respect those rules.

The ideas listed here are aimed at helping you find (and serve) young parents in your community:

- *Use the 'Developmental Checklist'. This brochure available through the national ARC office lists developmental milestones and ages at which most children typically achieve them. The checklist is especially appropriate for new or prospective parents because it can alert them to potential developmental delays in children. There are a number of possibilities for distributing the checklist. You might arrange to include a copy in the packages parents of newborns are given at the hospital, or to distribute the checklist to expectant and new parents at community clinics.*

- *Use the media. Radio and television public service announcements (PSA) and newspaper features are an effective and simple way of reaching large audiences at no cost. For example, radio stations usually only require 10, 20 or 30 seconds of written copy to air a PSA. Contact your local radio and TV stations to find out what their requirements are.*
- *Offer to provide in-service training on mental retardation to professionals or paraprofessionals (e.g. child care workers) likely to be in contact with young children with handicaps.*
- *Contact professionals in your community who work with children with mental retardation and their families. Physicians (especially pediatricians), nurses, social workers, special educators and ministers are usually eager to learn about community resources. Develop a special membership campaign aimed at professionals to increase their awareness of the ARC and its services.*
- *Identify all agencies in your area serving young children and make them aware of the ARC. Public and private schools, day care centers, city and county health departments, hospitals, clinics and social service agencies should be contacted.*
- *Provide confidentiality release forms to agencies and professionals likely to encounter young children with handicaps. Interested parents can sign a release and be referred to the ARC. Be sure to give release forms to hospital nurses and social workers.*

- *Ask for help. Although an agency which serves young children cannot give you the names of the families they work with, they might be willing to do the next best thing. Ask them to send information about your ARC to people on their mailing list. You can prepare the mailing and pay for the cost.*
- *Set up a speakers' bureau. To reach a large number of young parents, promote your speakers' bureau with professional associations like the local nursing association and groups such as the PTA.*

THE ESSENTIALS

Finding them is just a beginning step in serving young parents. If we are really committed to serving them, we have to insure appropriate programs are in place.

In this section, we will look at some of the basic programmatic needs of young children with mental retardation and their parents. We will also suggest some ways the ARC can help make sure those needs are met.

Pilot Parents

When children are newly diagnosed as having mental retardation, their parents may have a wide range of reactions. One thing is certain though. It will be one of the most difficult experiences of their lives.

Knowing there are others who have gone through the same experience and survived is a great help to new parents. Pilot parent or parent-to-parent programs are designed to offer young parents the unique kind of understanding and support that only a parent who has 'been there' can give.

Although there are many variations, pilot parent programs train a group of experienced parents of children with handicaps to work with parents of newly diagnosed children. The pilot parent provides emotional support and factual information to the young parent as well as the benefit of his or her experience in dealing with a handicapped child.

Pilot parent programs are an important service to offer young parents and one of the best ways to involve them. With careful planning, these programs can be easy to set up and operate with very little funding.

Programs have now been implemented in nearly every state. If there isn't already a pilot parent program in your community, it's time to start one.

Educational Advocacy

The Congress made a major federal commitment to insure that all children with disabilities receive full and appropriate educational services, when, in 1975, it enacted the Education for All Handicapped Children Act (P.L. 94-142).

Since that time, we have seen dramatic improvement in special education services, an increase in the number of children served by the public schools, and much more parental input into the education of their children with handicaps. Still, many parents have problems getting appropriate services for their children and many others (especially young parents) aren't aware of what they and their children are entitled to by law.

It is vitally important that the ARC movement be actively involved in monitoring special education services, advocating for improved special education programs and informing parents of their rights. An ARC which does not address educational issues cannot be considered responsive to the needs of young parents.

How can the ARC maintain active involvement in special education issues? An important first step is insuring the ARC maintains an education committee. If your ARC unit does not currently have an education committee, one should be created, and young parents should be asked to serve on it.

The education committee's first task should be to become informed about P.L. 94-142, state law and local policy. Other activities the committee might undertake are:

- *Sponsoring parent training on the Education for All Handicapped Children Act. It is especially important to cover parents' rights and development of the individual*

educational program (IEP) under P.L. 94-142.

- *Attending meetings of your school board and inviting representatives from your school district to ARC meetings.*
- *Keeping your membership informed about current developments, exemplary programs and major issues in education through your newsletter.*
- *Identifying sources for legal advice and representation for parents.*
- *Getting involved in your school district's planning and budgeting process.*
- *Training a group of volunteers who can assist parents at IEP or other meetings when requested.*

Early Childhood Learning Programs

Early childhood learning programs (sometimes referred to as infant stimulation or early intervention programs) provide educational and related services for infants, toddlers and pre-schoolers with mental retardation and other developmental delays.

Research indicates that both children and their parents can greatly benefit from early childhood learning programs. The child is helped to reach maximum developmental potential while the parent is helped to better cope with the child's disability.

Although some states have mandated comprehensive programs for handicapped children from birth, too many children below the age of 6 are not receiving the intervention needed to minimize future problems.

The ARC has traditionally been a leader in achieving high quality educational services for people with mental retardation and should continue to take the lead in developing and advocating for early childhood programs.

Young parents need to be informed about the benefits of early intervention, and adequate services should be available for their children. Here are some steps ARC units can take to make sure that happens:

- *Assign an ARC committee to look into your community's services for young children with handicaps. The committee can determine unmet needs, develop strategies to meet those needs and monitor existing services.*
- *Visit the early childhood learning programs in your area. Let staff and parents' groups know about the Association*

and what it does. Find out how your ARC can be a resource for them.

- *If your state has* **not** *adopted laws which address the needs of handicapped children between birth and the state's current lower limit for school age, find out what the ARC can do to advocate for programs with your state legislature.*

Respite Care

All parents need occasional time away from their children, but this is especially true of parents who have children with mental retardation and other handicaps. Many of these parents don't often get the chance to do the things most families take for granted -- like going out for dinner -- because there's no one to look after their child.

Respite care programs offer a solution by providing parents with temporary relief from the day-to-day care of their handicapped child. Care is provided by qualified, trained individuals enabling these families to function as much like 'normal' families as possible.

Although services are still not widely available, the concept of respite care is over 10 years old and many service delivery models have been developed. These range from informal parent babysitting cooperatives to more sophisticated programs offering a number of short and long-term options. What works in one community will not necessarily work in another, but some form of respite care should be available to parents.

What can the ARC do to create or expand respite care services? Here are just a few suggestions:

- *Learn more about respite care programs and their benefits. Educate ARC members and the community in general about respite care and why it is important.*
- *Determine the need for respite services. Survey families to find out how many would use respite care if it were available to them.*
- *Meet with other organizations and agencies serving*

persons with handicaps. Many successful programs have been implemented through the cooperation of several different groups.

- *If services aren't offered in your community, ask* **why not.** *Some agencies serving individuals with mental retardation do not view respite care as a priority. It's up to you to educate them.*
- *Explore what can be done legislatively to encourage the establishment of respite care services.*

Recreation Programs

Just like all children, children who are mentally retarded should have access to and participate in a variety of recreational activities.

As much as possible, children with handicaps should be integrated into recreation programs with their non-handicapped peers. Not all children, though, will be able to meaningfully participate in integrated recreation programs and for those children specialized services should be offered.

The ARC should see that a good year-round program of activities is available for all children with mental retardation regardless of the severity of their handicap.

If adequate recreation services aren't available in your community, here are some strategies your ARC unit should consider:

- *Find out what's available through other community organizations such as the YWCA, YMCA, churches, park department and civic organizations. If these organizations are not including handicapped children in their recreation programs, the ARC should encourage them to do so.*
- *Let the city council or other policy-making body in your community know about the need for recreation services for people with mental retardation. Be available to answer their questions.*
- *Identify unmet needs for recreation services and encourage service providers to create or expand recreation programs.*
- *Contact local schools and other agencies to explore the possibility of cosponsoring recreational programs with your ARC unit.*

GOING A STEP FURTHER

Although you couldn't consider them 'essential', many ARCs have developed services which address specific needs of young children and their parents. Just a few examples of the creative solutions ARC units have found to identify and involve young parents are described in this section.

Toy Lending Libraries

Toys are important in fostering intellectual, physical and social growth in children. When children have handicaps, toys can also be important tools in developmental intervention.

A toy library makes it possible for a child to be exposed to a variety of developmentally appropriate toys at no cost to parents. Many ARC units operate toy libraries because they are a simple and inexpensive way to serve young children. There are several good sources of information on how to organize and operate toy libraries.

Car Seats

Many states have recently enacted strict child passenger safety legislation to reduce the number of children injured or killed in car accidents. These laws require the use of special restraints and equipment for children under certain ages.

Several ARC units have used this to their advantage by setting up car seat loan programs. These programs sell car seats at discount prices to parents who can later exchange them for larger seats as the child grows.

An initial investment is required, but the results can be well worth it. Not only is this program a valuable service to parents but it also gives the ARC a great deal of visibility in the community.

Adaptive Equipment Exchanges

One ARC unit has found an unusual way to involve parents of children with multiple handicaps. These children often need special equipment to increase their independence in self-care and mobility. The ARC purchased or received donations of adaptive equipment such

as wheelchairs, strollers and other devices and made the equipment available to multiply handicapped children on loan. When a child outgrows a particular device, the parent returns the equipment to the ARC. Since adaptive equipment can be very expensive parents will want to take advantage of this service.

Parent Libraries

Parents whose child was recently diagnosed as having mental retardation usually have an almost overwhelming need for practical information to help them cope with their child's disability. As the child grows and new problems arise, parents will continue to need this type of information.

Since public libraries may only have limited resources for these parents, many ARCs have started their own libraries. A parent library need not be extensive to be helpful. Many materials are available free or at low cost from the ARC National Headquarters, federal and state governments, and many other organizations. As an example, some of the publications routinely distributed to young parents through the ARC national office are:

- *Early Intervention Services for At Risk and Developmentally Delayed Children Below School Age*
- *The Mentally Handicapped Child Under Five*
- *Helping Mentally Retarded Infants Learn*
- *Primer for Parents of a Mentally Retarded Child*
- *One Step at a Time*

- *A Helpful Guide in Developmental Training*
- *Developmental Checklist for Young Children*
- *Toilet Training Your Retarded Child*
- *An Overview of Down's Syndrome*
- *Your Down Syndrome Child*
- *Make the Most of Your Baby*
- *Pocket Guide to Federal Help*
- *Practical Advice to Parents*
- *Educating Handicapped Children*
- *Mainstreaming Mentally Retarded Students in the Public Schools*
- *Monitoring the Right to Education*
- *The Parent Professional Partnership*
  - *The Right to Education*
  - *Classroom Programming*
  - *The Partnership*

A LOOK AHEAD

Whenever the ARC is successful in involving young parents, an outgrowth of that success will be an increase in membership. At least some of the young parents who join the ARC will be interested in taking an active role in Association affairs and it is important that we nurture their interest.

How can the ARC keep young parents interested and build their commitment to the movement? ARC leadership must see that young parents are:

- *welcomed*
- *given opportunities to participate*
- *involved with appropriate committees*

- *challenged by issues and special projects, and*
- *trained for leadership roles.*

The ARC must reach out to parents of young children with mental retardation, educate them, meet their needs, meaningfully involve them and prepare them to assume ARC leadership in the future.

IT'S VITAL -- TO OUR FUTURE AND THEIRS.

The techniques described in this handbook have been used successfully by ARC units throughout the country. If you need more information or would like to share your own success stories, contact the ARC National Headquarters.

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